



A GUIDE

STARTING A

self-help group

FOR PEOPLE WHO HAVE HAD A
STROKE AND FOR CAREGIVERS



A Guide to Starting a Self-Help Group for People Who Have Had a Stroke and For Caregivers © 2003, Heart and Stroke Foundation of Ontario

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table of contents

Acknowledgements	v
Foreword	vii
What is a Self-Help Stroke Group?	1
The Benefits of a Self-Help Group	1
Mutual and Practical Support	1
Education	2
Social and Recreational.....	2
Access to Resources	3
The Early Planning Stage of a Self-Help Group	3
Connecting with Existing Self Help Groups.....	3
Determining the Purpose and Goals of the Groups	4
Recruitment of Members	5
Time, Frequency and Length of Meetings	7
Planning the Activities of the Group	8
Meeting Space.....	8
Costs	9
Considerations When Facilitating a Self-Help Group	10
Preparation of the Agenda.....	10
Enhancing Participation of Members in the Group	11
Confidentiality.....	11

Evaluation.....	12
Leadership of a Self-Help Group	13
Role of Professional Staff in a Self-Help Group	15
A Hybrid Model for Self-Help	15
Expectations about Decision Making	16
Ground Rules about Talking	18
Record Keeping	18
Checklist for the Initial Meetings	20
Before the Meeting.....	20
Preparation of Agenda	21
After the Meeting	23
Dealing with Some Potential Issues	24
Available Resources	28
References	35

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Foreword

Having a stroke can lead to profound changes in the life of the stroke survivor, his or her family and caregivers. We know that social support from others, who have shared this experience, can be very helpful. Self-help groups can provide that social support. This guide is designed to assist individuals who are willing to take a leadership role in organizing a self-help group for persons who have had a stroke and/or caregivers. It will also provide you with information about existing groups you may wish to connect with.

The development of this guide is part of a series of pilot projects funded by the Ministry of Health and Long-Term Care as a component of the Ontario Stroke Strategy. The Southeastern Ontario Regional Stroke Steering Committee identified supports for stroke survivors in rural areas as a priority for action. The Heart and Stroke Foundation of Ontario and the Ontario Community Support Association, working with other provincial organizations to enhance the resources available for stroke survivors in the community, agreed that the pilot project in the Southeastern Ontario Region should address the issue of social support.

We hope that persons who have had a stroke, their caregivers, health care providers and volunteers will find this a useful resource in promoting and developing self-help groups.

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Association

What is a Self-Help Stroke Group?

A Self-Help Stroke Group is a group of two or more people who come together to share their experiences with stroke.

A Self-Help Group for Stroke Caregivers is a group of two or more people who come together to share their experiences caring for a person who has had a stroke.

We each have different strengths, attitudes and ways of coping with stroke. Self-help groups provide participants with an opportunity to access that inner wisdom and share it with others.

Benefits of a Self-Help Group

MUTUAL AND PRACTICAL SUPPORT

- Opportunities to share experiences, frustrations and joys
- The realization that you are not alone; there are other people who know and understand what you are going through.
- Support offered to other participants.
- Laughter.
- Group problem-solving and sharing of ideas.

- Help to recognize and accept feelings that have arisen as a result of the stroke and validation of those feelings.
- Opportunities to examine coping styles and strengths.
- Assistance dealing with emotions like anger, guilt, stress, loneliness and grief.
- Opportunities to learn new ways to communicate with someone who has had a stroke.

EDUCATION

- Members educate each other by sharing their experiences.
- Stroke resources are provided to participants.
- Attending an educational session may seem less threatening than joining a self-help group.

SOCIAL AND RECREATIONAL

- Meeting new people in the same circumstance.
- Opportunities to socialize and reduce feelings of isolation.
- Celebrating special events.
- Sharing a meal or light refreshments together.

ACCESS TO RESOURCES

- Increased awareness and access to services in the community.
- Increased awareness and access to hospital services.

The Early Planning Stage of a Self-Help Group

There are a number of decisions to make when organizing a self-help group. You may wish to consider having a small planning committee of committed and interested people, to make some of the decisions required in setting up a self-help group.

This section outlines some of the issues that need to be considered when setting up a self-help group.

CONNECTING WITH EXISTING SELF-HELP GROUPS

Before proceeding to develop a self-help group for people who have had a stroke or for caregivers, the first step is to investigate what is currently available in your community. Your needs may be met by an existing group. There may be a caregiver support group that is not stroke specific, yet covers many of the same issues/concerns you are facing.

There are two key ways to find out about existing self help groups:

1) Contact the Ontario March of Dimes' Stroke Recovery Network. You may wish to become a member of the local peer-support chapters in operation throughout Ontario. Also, the Network provides individuals with resources they need to run successful peer-support groups.

2) Contact the Ontario Self Help Network to obtain a listing of Self-Help Centres in Ontario.

More information is available about these two organizations in the "Resources" section of this guide.

DETERMINING THE PURPOSE AND GOALS OF THE GROUP

The initial planning committee will need to be clear about why people are being asked to come together? What would they like to achieve? The answers to these questions are very important and effect all other decisions related to organizing and running a self help group for stoke caregivers or for people who have had a stroke. Participants must have their needs met, given the time, energy and arrangements that will need to be made in order to attend a meeting (e.g. transportation, arranging care while away). Discussing and validating with participants the purpose and goals of the group is a way of beginning to build interest and commitment to the self-help group.

RECRUITMENT OF MEMBERS

Target Audience

Define who the group is for, for example, people who have had a stroke, caregivers, and stroke survivors of a specific age group.

The Ontario Self –Help Network recommends that good candidates for self-help are people who are able to give and receive support with others who share a common concern. Inappropriate candidates for self-help include people who are in active crisis, suicidal, actively using drugs and alcohol or unable to conform with the behavioural expectations of the group.

Size of the Group

A group size of 5 to 15 people is recommended to allow everyone an opportunity to participate.

Timing

Consideration should be given to the best time to recruit people to participate in a self-help group. Each person who has had a stroke differs in the severity of their stroke, their road to recovery, their coping skills and their support system.

Recovering from a stroke takes time and the extent of recovery will vary considerably among individuals. Consequently, people may be more receptive to joining a self-help group after they have returned home and have begun to readjust to the changes caused by their stroke.

Strategies for Recruiting Members

There are a number of strategies that can be used to promote a self-help group to the community, people who have had a stroke, caregivers, health care staff and volunteers:

One of the most effective ways of recruiting members is word of mouth. Participants in your group have an important role to play in promoting the group (e.g. neighbours, friends, family).

Prepare a flyer that includes the name of the group, purpose, meeting dates, location, time, place and cost (if any). These flyers could be posted at libraries, schools, community centres, and church and community groups.

Talk to groups that provide services to people who have had stroke and share information about the group. Examples of groups include: hospitals, community rehabilitation agencies, community support service agencies, community health centres, community care access centres and social service agencies, public health departments, doctors' offices, walk-in clinics, long-term care facilities, local Heart and Stroke Foundation offices, and pharmacies.

Write articles for local community newspapers, church bulletins or agency newsletters.

Write press releases for local radio and television stations.

Work with the Stroke Recovery Network. They support membership recruitment through publicity, materials, an annual Awareness Month and the Stroke Registry.

TIME, FREQUENCY AND LENGTH OF MEETINGS

Meetings may be held weekly, monthly, bi-monthly and quarterly. The participants of the group need to determine the time of day, frequency and length that best meets their needs.

Earlier in the day may be more suitable for stroke survivors when energy levels tend to be higher. The time required to travel to the meeting should also be considered.

Determining the length of the meeting will be based on issues like energy level, transportation and responsibilities at home. In addition, a limited attention span, another side effect of a stroke, may restrict the length of the meeting.

Another issue to address is how often the group will meet. Is the group going to be time-limited or ongoing?

The organizer should consider the support that is needed to allow participants to attend and how to eliminate some of the barriers to attendance. Examples of barriers may include transportation and arranging care for a stroke survivor while away from home.

PLANNING THE ACTIVITIES OF THE GROUP

The group should decide the amount of structure that is needed to meet their needs. There is no right or wrong. It is important that participants are involved in decision-making about their group.

MEETING SPACE

A regular meeting space in a central location is preferable. Some factors to consider include:

- Is the location wheelchair accessible?
- Is the location close to a public transit system?
- Is there wheelchair accessible parking close by?
- Are there places to put up signs, directing people to the meetings?
- Is the space available for an extended period of time?
- Is the space quiet and private to encourage participants to share their experiences and feelings?
- Can the space accommodate potential expansion of the group?
- Does the meeting room have space for those with assistive devices to move around easily?
- Are the washrooms close to the meeting space and are they wheelchair accessible?

- Are there facilities and equipment to serve light refreshments?
- Can the furniture be moved to accommodate the desired room set-up? Do the chairs have armrests that are sturdy and easy to sit in and get out of?
- Is the temperature of the room adjustable?

Set Up - A circle of chairs allows for easy eye contact and facilitates communication. It also reinforces equality among participants.

COSTS

There are costs incurred for organizing and running a self-help group. Examples include rental of the space, photocopying, use of audiovisual equipment and refreshments. The organizer of the group could search for organizations that are willing to provide space at no cost (e.g., churches or not-for-profit organizations). Participants may be asked to take turns to provide refreshments. As an alternative, participants could be asked to make a weekly donation or yearly contribution to help cover the cost of running the group. Where fundraising is done, consideration should be given to obtaining a registered charitable number or joining the Stroke Recovery Network as a chapter. Whatever the decision, the financial contribution should not be a barrier to participation.

Chapters of the Stroke Recovery Network receive support in the management of their finances, use of an existing charitable number for fundraising purposes, and can benefit from access to meeting space at Ontario March of Dimes locations. The materials and publicity provided by the Stroke Recovery Network can help reduce costs and increase the profile of your group in your community.

Considerations When Facilitating a Self-Help Group

PREPARATION OF THE AGENDA

Meetings of the self-help group serve as a vehicle for building interest, trust, support and cohesion. Each meeting should have an agenda so that participants know the focus of the meeting. The amount of formality and structure may vary considerably, to meet the group's needs. However, it is important for the group's integrity that all items on the agenda get discussed and changes are kept to a minimum. Any changes should be negotiated with the group. Agendas are important because they

- Help participants to focus on areas that are most important to them
- Facilitate the decision making process

- Are a tool that helps the leader plan for the meeting
- Enhance the creditability and organization of the self-help group

For examples of agenda items at the initial meeting of the self-help group, refer to the section "Checklist for Initial Meetings."

ENHANCING PARTICIPATION OF MEMBERS IN THE GROUP

Involving participants is a good way to increase commitment to the group. Some ways to involve participants include:

- Calling participants to remind them about meeting dates. This is especially important given the memory loss that often occurs after a stroke.
- Welcoming members as they arrive.
- Starting the meetings with introductions to help new members feel welcome.
- Setting up the chairs in a circle to encourage sharing and mutual support.
- Sharing the preparation and clean up of refreshments.
- Taking turns to lead a discussion on a particular topic. Some possible topics include: finding support, driving after a stroke, dealing with depression, dealing with the emotional and physical issues of stroke, handling money, traveling after a stroke.

- Taking turns to research speakers and topics that may be helpful to the group.

CONFIDENTIALITY

Early on in the development of the group, a discussion about confidentiality is appropriate. Participants should specifically discuss expectations about what can be shared outside the group and what should remain inside the group.

EVALUATION

Requesting feedback from participants is an effective way to ensure that the group is meeting their needs. Asking questions will give the planners some good insights about the needs and direction the group would like to take. All feedback should be shared with the group and appropriate changes made based on group discussion.

You may wish to break into smaller groups for individuals who may be hesitant to speak up in a larger group. A recorder should be assigned to report back on the discussion. Here are a few basic questions that can provide helpful feedback:

- What is most helpful about the self-help group?
- What is least helpful about the self-help group?
- Do you have any suggestions to help make the group more effective?

- Would you be interested in assuming a more active role in the organization of the group?

- Is the location accessible to you?

- Is the frequency of meetings adequate to meet your needs?

- Is the length of the meeting appropriate?

- Is transportation a difficulty for you?

- As a caregiver, does arranging care or coverage for the person who has had a stroke, pose an obstacle to your participation in the self-help group?

Some participants may prefer written or one on one feedback, instead of speaking in front of the group. Thought should be given to how feedback is obtained. The severity of the stroke will affect the cognitive and language abilities of participants.

Leadership of a Self-Help Group

The person, who knows best about what it is like to have a stroke, is indeed the person who has had a stroke. This is also true for the caregiver. There is a real opportunity through self-help for individuals to tap into this expertise and wisdom that they have and share it with others.

The severity of the stroke is a significant factor in the abilities of participant to take on a leadership role in a

self-help group. Each individual who has had a stroke has varying abilities in terms of language capacity, memory loss, cognition, mobility etc. Consequently, depending on the individual who participate in the group, it may be wise to consider a shared leadership model. This will also reduce leader burnout, build a strong leadership foundation for the group and enhance participation in the group.

Leadership is an important element in the success of a self-help group. Some of the roles of a leader or facilitator include:

- Organizing the group.
- Determining the focus of the group (what are the desired outcomes).
- Making people feel welcome.
- Encouraging participation.
- Facilitating the discussion.
- Assisting with group decision-making.
- Evaluating the success of the group.

Interviews with existing self-help groups, identified the following critical skills for leaders: a sense of humour, the ability to listen, respect for the contributions of participants, and the ability to continuously redirect issues, concerns and decisions back to the group. For example, if one participant recommends that for the

next three weeks he believes that guest speakers should be invited to present on depression and stroke, the facilitator would not respond by stating his/her opinion but rather may redirect the question back to the group and ask what others think about this idea:

- Are there other topics where further information would be helpful?
- Who are some possible guest speakers?
- What amount of time of the meeting would you like to allow for this information? etc.

There are a few decisions that should be made early on in the development of the group to avoid conflicts later on. It is recommended that the participants of the group make these decisions jointly.

For more information refer to the section "Considerations When Facilitating a Self-Help Group" and the "Checklist for the Initial Meetings."

ROLE OF PROFESSIONAL STAFF IN A SELF-HELP GROUP

Consideration should be given to the role of a professional/paid staff person from a health care organization in the development and ongoing support of a self-help group.

In a true self-help model, participants organize, run, support and control the group. Therefore, one of the primary roles of the professional in a self-help group is

to facilitate the development of the group and nurture the leadership. It is not the professional's role to take control of the group or to assume the responsibilities of the group. In fact, participants may feel inhibited if they perceive the professional as the "expert" who knows best. Some examples of the role of a health care professional include:

- Assisting with recruitment.
- Initially helping with start-up and then ensuring ownership and control rests with the participants.
- Sponsoring the group by providing the meeting space, refreshments, telephone, photocopying, advertising space (bulletin boards, newsletters etc.)
- Providing education on specific topics and areas of concern as requested by the group.
- Providing or assist with accessing resources on stroke.
- Help group to connect with the local self-help center, existing self-help groups and networks.

A HYBRID MODEL OF SELF-HELP

There is also a hybrid model of self-help model. The professional or paid staff person facilitates the group in a way that uses the self-help principles/strategies. This may occur as result of the health status of participants or be a part of the start up phase of a group.

Professionals/paid staff have an important role to play in bring caregivers or persons who have had a stroke together for the purposes of self-help. The research indicates that approximately one-third of all self-help groups are indeed begun by professionals/paid staff. It is important to know when is the appropriate time to step back from the role of founder and leader and let participants assume more ownership and control of the group.

Possibly over time the group is transitioned from a professional led group to a member/participant led group. A number of questions should be considered in advance:

- What is really meant to occur by the transition?
- How will it be done?
- Are skills and experience of the people in the group who could have leadership role been identified and encouraged?
- What is the appropriate time to do it?
- Who should be involved?

The professional staff could provide behind-the-scenes support of the new leadership by occasionally touching base and problem solving (as required). Further information about transitioning from a professionally led group to self-help and also tips for the helping professional are available through the Self-Help Resource Centre.

EXPECTATIONS ABOUT DECISION MAKING

Determine how the group would like to make decisions: by consensus, simple majority, taking a vote through a show of hands or secret ballot? The method chosen may depend on the situation. Decision making through consensus will have the maximum benefits in terms of building bond / trust between participants. In order for this to occur, there needs to be an environment where participants feel comfortable to express their opinion freely.

Where the issue is very controversial, discussion has been exhausted and consensus has not been reached, a secret ballot vote may be appropriate. Participants can express their opinion freely, without being intimidated.

GROUND RULES ABOUT TALKING

Establish rules and expectations about talking. An open discussion about the ground rules for talking helps to provide a response to dealing with a participant who monopolizes conversation in the group. Some considerations include: equal time to speak, raising hands to contribute, proceeding in turn in a circle, and speaking once then waiting until others have had an opportunity to speak. The rules and procedures developed should be kept as simple as possible to help get the job done. The ultimate goal is to make the participation in discussion easy for participants – there is some order and respect for each member's contribution.

RECORD KEEPING

Minutes serve as a formal record of the decisions made at the meeting (e.g. tasks assigned, who is responsible, deadlines). Thought should be given about what kind of record keeping/minutes are necessary? Should attendance be taken at each meeting? If so, what is the purpose of this information? How will it be used?

Checklist for the Initial Meetings

Before the Meeting

- Arrange publicity to advertise the first meeting.
- Make reminder phone calls to participants.
- Purchase nametags and markers.
- Organize the room set up, for example, circle of chairs (not around a table), a table to sign in and get nametags, flip chart and markers (if necessary).
- Organize and set-up refreshments.
- Assign people to meet and greet at the entrance.
- Post the agenda on flip chart or print and copy it as a handout.

Checklist for the Initial Meetings

Preparation of Agenda

It is recommended that the planning group assist in organizing a self-help group by making a number of preliminary decisions. After the membership has settled and there is regular attendance at the meetings, it would then be appropriate to bring forward some rules of operating and ask participants to discuss and validate them.

First impressions are important and you do not want to overwhelm participants at the first meeting. The agenda item, which should receive a higher priority, is the purpose and goals of the self-help group. It is important for participants to reach a common understanding right from the first meeting. The following list presents potential agenda items you may wish to consider over the first few months of the group's operation:

- 1.** Introductions
- 2.** Sharing and discussion of the purpose and goals of the self-help group
- 3.** How the group wishes to run
 - a.** Expectations about confidentiality?
 - b.** How decisions are to be made?

Checklist for the Initial Meetings

- c.** What kind of record keeping is necessary?
(e.g., minutes)
 - d.** How formal or informal should the group be?
(e.g., elected positions, agenda)
 - e.** Finances – Are there any expenses to be covered? Are dues going to be collected?
 - f.** What is the name of the self-help group?
 - g.** What is the role of a paid staff person or professional in the self-help group?
- 4.** Sharing stories and experiences/Checking in
 - 5.** Planning activities for the group (sharing experiences, social/recreational, educational, physical fitness, guest speakers, video, fundraising, advocacy, selection of key topics such as coping strategies, dealing with depression, vacationing post stroke)
 - 6.** Involvement of participants in organizing the group (assistance with phone calls, record keeping, collecting money, refreshments, facilitating group discussions, meeting and greeting at the door)
 - 7.** Evaluation – feedback about the meeting
 - 8.** Next meeting: plans for the agenda, date, time and location confirmed
 - 9.** Closing thoughts and thanks to participants for attending
 - 10.** Informal socializing

After the Meeting

- Review the results of the evaluation/feedback provided by participants.
- Bring recommendations back to the participants or planning body and make the appropriate changes, based on group feedback.
- Follow up with any decisions made at the meeting.
- Confirm meeting location, time and date for the next meeting.
- Follow up with participants who indicated they were interested but did not attend. Assist to resolve any barriers to participation (e.g., transportation)

Dealing with Some Potential Issues

THE PROBLEM — SOME SOLUTIONS

One participant dominates the conversation and does not allow others to participate.

- Initially set up some ground rules with the group about time limits for speaking.
- Ask for input from a participant who has not yet had the opportunity to speak during the meeting.

Burn out of the leaders or organizers of the group.

- Clearly identify all the tasks that need to be completed to run the group. Ask for volunteers to complete specific tasks. Break down the responsibilities to make the tasks more manageable.
- Bring the issue of the workload and resulting stress to participants in the group and let the group problem-solve this issue.

High turnover of participants.

- Evaluate at regular intervals to assess if the needs of participants are being met.

- Follow-up with participants to find out why people are not returning.
- Discuss changes that can be made to address some of the barriers to participation.
- Put measures in place to remind participants of the meeting dates.

The group is taking a long time for participants to feel comfortable/develop trust and thereby meet its goal of providing emotional support.

- Share the responsibilities of the group.
- Welcome new members.

Note: Relationships and a level of trust and comfort must develop before participants can feel comfortable taking risks and sharing experiences. According to the literature it may take six months to a year before there is stability within the group.

Trouble recruiting caregivers and people who have had a stroke to participate in a self-help group.

- Focus on education, which is a natural stepping-stone to the development of a self-help group. People may be more receptive to receiving information about stroke treatment than to joining a self-help group.

Note: *The Living with Stroke Program produced by the Heart and Stroke Foundation of Ontario can be tailored to meet the specific information needs of stroke survivors and caregivers.*

- High numbers do not always equal success. The quality of the interactions, adequate opportunities to contribute, and meeting the needs of individual group members are more important indicators of success.
- Refer to the section on "Recruitment of Members" for more suggestions.

There is conflict among participants in the group.

The Self Help Connection in Nova Scotia promotes the practice of "putting the conflict on the table". Following are their identified steps to work toward resolution of the conflict:

- Agree to put the conflict on the table.
- Have each person define the problem.
- Have each person state his or her needs.
- Have an observer restate the problem.
- If both parties agree that this accurately reflects the problem, have everyone brainstorm about possible solutions.

- Make a list of these solutions.
- Identify two or three solutions that seem workable.
- Narrow the list to one solution.
- Make a commitment to try the solution.
- Evaluate the solution within a certain period of time.
- If the solution does not work, try the steps again.

Available Resources

There are many resources available to assist in the planning of a self-help group. Topics to review include stroke, caregivers and self-help groups. There is a lot of opportunity to build on the expertise and experiences of other people.

A good place to start is to investigate whether or not there is a stroke group or caregivers' group already existing in your community.

Following is a list of some key resources, including Web sites:

THE SELF HELP RESOURCE CENTRE

40 Orchard View Blvd., Suite 219,
Toronto, ON M4R 1B9

Telephone: 416-487-4355,

Outside Toronto: 1-888-283-8806

Fax: 416-487-0344

Web site: www.selfhelp.on.ca

E-mail: shrc@selfhelp.on.ca

The goal of the Self Help Centre is to increase awareness about self-help in the community and among helping professionals and to facilitate the growth and development of self-help groups, networks and

resources. The following programs are offered:

- Information about and referral to more than 500 self-help groups.
- Community outreach and promotion.
- Consultation and training.
- Special projects.

ONTARIO SELF-HELP NETWORK

E-mail: oshnet@selfhelp.on.ca

The Ontario Self-Help Network (OSHNET) provides consultation, networking, and training and information services to increase the capacity of self-help/mutual aid initiatives throughout the province of Ontario. The Ontario Self-Help Network is a program of the Self Help Resource Centre. Many of the materials are available free of charge to not-for-profit organizations. Here is a sampling:

Transitioning from Professional to Member Leadership – Workshop

Steps for Evaluating Your Group – Workshop

Self-Help 101 – Fact Sheet

Tips for the Helping Professional – Fact Sheet

Confidentiality in Self-Help Support Groups – Fact Sheet

Shared Leadership Workbook

Why re-invent the Wheel? Sample guidelines, pamphlets and other tools from groups

List of Self-Help Centres Across Ontario

ONTARIO MARCH OF DIMES

STROKE RECOVERY NETWORK®

10 Overlea Blvd., Toronto, Ontario M4H 1A4

Telephone: 1-888-540-6666

Website: www.srn.ca

The Stroke Recovery Network® is a specialized service assisting stroke survivors with long-term rehabilitation and re-integration into community life. Ontario March of Dimes has an extensive range of services that help maximize the independence, personal empowerment and community participation of people with physical disabilities. The following services are offered:

The Stroke Registry: This service for stroke survivors, caregivers and professionals, provides up-to-date information on stroke recovery and rehabilitation. Registration is privacy-protected.

Peer Support Chapters: Social and emotional supports necessary during recovery, and ongoing maintenance and integration in the community are provided through Peer Support Chapters. Participation gives members opportunities to explore the

psychological and social impacts of stroke, to exchange information and resources, to help learn new care skills, and to create a social network for mutual aid and support. Chapter members include: stroke survivors, family members, caregivers, health care providers, volunteers and friends.

Caregiver Support: Links family members and caregivers with in-home assistance for activities of daily living, provision of assistive devices, information and facilitation of home modification grants. Caregivers who are members of peer support chapters can also benefit from social and emotional support, reducing their levels of anxiety and feelings of isolation.

Information Services: Up-to-date stroke information and resources on the Internet and through publications, conferences and seminars are

Stroke Recovery Research: The goal is to research the long-term needs of stroke survivors, and to help direct more government funding into this much-needed area of service.

HEART AND STROKE FOUNDATION OF ONTARIO

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Fax: 416-489-6885

E-mail: mail@hsf.on.ca

Web site: www.heartandstroke.ca

Here is a brief listing of some of the resources available free of charge from the Heart and Stroke Foundation:

The Emotional Journey – Understanding

Emotional Issues After Stroke (brochure)

Information for the survivor and caregiver

Heart & Stroke Health Show (videos)

Hosted by Dini Petty and featuring the stories of real-life Canadian heart disease and stroke survivors.

How Stroke Affects Behaviour (brochure)

Discusses some common behaviour changes after a stroke such as paralysis, neglect, social judgment, memory and emotional lability.

Jack’s Story (paperback book)

A storybook for children to understand what is happening when a loved one suffers a stroke.

Lets Talk About Stroke (paperback book)

A guide containing basic information about stroke and what to expect during recovery.

Living With Stroke (binder/video)

An education and support program for stroke survivors and caregivers. Visit www.heartandstroke.ca/stroke for a list of organizations offering the Living With Stroke program.

Memory Loss After Stroke (brochure)

A practical guide to understanding changes in memory as a result of stroke, with tips for the survivor and caregiver on managing memory loss.

Strokeline (newsletter)

A quarterly newsletter providing useful information for survivors and caregivers about living a quality life after stroke.

Stroke (brochure)

A Guide for the Family: general information about stroke, risk factors, treatment and the family’s role in recovery

Tips and Tools for Everyday Living: A Guide for Stroke Caregivers (binder and video)

This guide provides practical knowledge and skills needed by the people who provide care day in and day out to people who have had a stroke. Areas covered include anatomy of stroke, psychosocial effects, communication, leisure activities, mobility and skin care, routine activities of living, cognitive and perceptual problems, meal assistance and hydration, specific behaviours, managing continence, risk factors for stroke.

For more information about Heart & Stroke patient resources, call:

416-489-7100 or

1-888-473-4636

or visit www.heartandstroke.ca/stroke

OTHER WEB SITES

Caregiver Network: www.caregiver.on.ca

416-323-1090

Caregiver Network Inc. is a resource centre created to help caregivers of the elderly and ill. The goal of this network is to make caregivers' lives easier by providing information on the Internet and via their newsletters.

National Stroke Association: www.stroke.org

1-800-787-6537

The National Stroke Association is a United States non-profit organization aimed at reducing the incidence and impact of stroke. It provides education, advocacy, public policy, resources, research, services and community-based activities in prevention, treatment, rehabilitation and recovery.

The Aphasia Institute: www.aphasia.on.ca

416-226-3636

The Aphasia Institute is dedicated to reducing language barriers to full life participation at local, provincial, national and international levels. They are involved in advocacy and awareness, education and training, applied research and resource development

References

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Making Self-Help/Mutual Aid Work: The Resource Kit. Ontario Self-Help Network. A Program of the Self Help Resource Centre, March 2000.

Pat Stewart, Leader of Self Help and a stroke survivor. Belleville, ON. Interviewed on November 6, 2002.

Stroke Clubs in Nova Scotia: How to Start One in Your Community. Self Help Connection, Nova Scotia, Canada

Stroke Survivors' Group and Stroke Caregivers' Group, St. Mary's of the Lake Hospital, Providence Continuing Care Centre, Kingston ON. Interviewed on November 6 and 7, 2002.